

Gaps in Care across Chronic Diseases in Delaware: A Focus on Cancer and Renal Disease

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In the state of Delaware four of the five leading causes of death are chronic diseases, and around 50% of deaths stem from cancer and cardiovascular disease alone (Delaware Department of Health and Social Services, 2019). The state needs organizations and projects to provide sufficient access to resources and educational programs in order to assist the large number of Delawareans impacted by these chronic diseases and to prevent their onset. It is critical to analyze the gaps in the programs and webpages currently in place to uncover the areas for improvement. This analysis will briefly cover a few of the identified gaps present in the initiatives for cancer and kidney diseases in Delaware, as presented by the Delaware Chronic Disease Coalition and other available resources.

Gaps in Cancer Care in Delaware

The state of Delaware has historically had difficulties battling cancer on a population level. In the early 1990's, the state had the highest rate of cancer deaths (Petrilli, 2017). In 2001 the establishment of the Delaware Cancer Consortium made drastic changes and the mortality rate has been recorded to drop twice as fast as the national average since (Petrilli, 2017). While the state has made drastic changes that have advanced cancer Care in the last 20 years, there are still unique gaps in care that exist for Delawareans battling the disease.

Social/Emotional Resources

Despite cancer impacting a large number of Delawareans, there are limited resources available to assist in the social and emotional difficulties associated with the diagnosis. The resources that are available are difficult to navigate and require mild technical prowess. This impacts not only current cancer patients and their families, but also patients entering remission that may still have emotional and social burdens. Specifically, this gap impacts individuals that are not experienced with navigating websites and utilizing search engines, such as the elderly and lower socioeconomic status patients; 25% of individuals over the age of 65 and 43% of Americans that identify as low-income do not have desktop or laptop computers in the household (Mitzner et al, 2010; Vogels, 2021). It has been proven that social support to individuals diagnosed with cancer is critical to navigating treatment and coping with non-treatment related side effects of the disease (Bloom and Kessler, 1994). In order to alleviate this obstacle, it is

important that the state support nonprofit organizations that aid in providing free resources to residents such as support groups and therapy sessions. Wake Forest Baptist Comprehensive Cancer Center offers various Zoom sessions, as well as in-person groups that provide places for individuals with similar battles to come together and comfort one another. The in-person events typically include an activity or entertainment such as chair yoga, creating art pieces, or listening to classical music. Implementing similar events at the various cancer centers in Delaware could provide the support that patients may lack. The state could increase promotions of the programs that are currently in place to all cancer patients and extend their outreach. Despite resources such as Cancer Care Coordinators being present, they are not advertised to cancer patients and information about the program is not easily accessible. A web page where patients can access the appropriate resources and health information along the entire trajectory of their illness would allow for better health management alongside the ever-changing needs (Gille et al., 2021).

Financial Assistance

Another category of cancer resources that is lacking in Delaware is financial assistance. The Delaware Department of Health and Social Services offers a program that provides free cancer treatment to uninsured patients for up to two years, assuming they meet designated requirements (*Cancer treatment program provides financial help for uninsured*

patients). While this is extremely helpful to the population of uninsured patients, there are few resources available to individuals with any level of insurance coverage and with various premiums. On average, the medical costs in the initial, continuing, and end-of-life phases for cancer patients were found to be \$41,800, \$5,300, and \$23,500, respectively (*Cancer Costs*, 2020). The price for prescriptions varied across cancer patients from \$600 to \$24,000 a year (*Cancer Costs*, 2020). Expenses for cancer patients extend beyond treatment, to include prescription medications, appropriate housing, transportation, and more. Financial assistance is crucial for improving cancer outcomes, as patients defined as having great financial distress were nearly twice as likely to not adhere to oral medications, as well as chemotherapy appointments. Financials are often not discussed within medical appointments either, as only 34% of patients in the study reported having a member of their medical practice discuss the burden that costs can inflict (Smith et. al, 2019). The three largest hospital systems in Delaware (ChristianaCare, Bayhealth, and Beebe) do offer nurse navigation to patients, however information specifically

for financial navigators is not apparent. Financial navigators are professionals routinely found in larger cancer centers that assist patients on an individual level with specific needs relating to expenses in and outside of treatment. Implementing specialized navigators could assist in connecting patients with appropriate resources and alleviating the financial burden associated with cancer care in Delaware.

Furthermore, there are limited resources available to individuals after they have beaten cancer that assist them in transitioning back to normal life. Around one third of cancer survivors continue to suffer with residual effects of their cancer diagnosis during remission (i.e., depression, anxiety, guilt, sleep disturbance), and even recurring symptoms (Wu and Harden, 2015). Other states such as Maryland and North Carolina have programs in place that assist patients in obtaining life-appropriate jobs, developing healthy habits to contribute to their wellbeing, and assistance in navigating the emotions faced during remission (*Cancer survivorship program ; Survivorship Care Plans & Clinics*, 2021). This impacts specifically patients in remission and their support systems. A six-week Delaware program exists that helps individuals battle the mental effects of survivorship, however limited information is available (*Cancer: Thriving and surviving program*). There was no information about where the classes were held or in which region of the state. Implementing more programs comparable to this that are more easily accessible throughout the state and have essential information easily available to patients would be an appropriate solution to pursue.

Resources for Marginalized Patients

There is a general lack of medical programs specializing in providing equitable care for disadvantaged populations in Delaware. There are a vast number of individuals that fall under this umbrella including many ethnic groups, individuals that speak a language other than English, disabled patients, and people of other sexual and gender identities. It is undeniable that these groups tend to have different cancer outcomes than individuals that are privileged within our society; Afshar found that 21 of the 29 cancer types demonstrated significantly lower survival rates for members of marginalized populations (Afshar, 2020). The lack of programs and initiatives to overcome the lower survival rates for these individuals impacts not only the patients that are members of minority groups, but also their support systems. There are additional impacts on individuals in remission that are members of minority groups, however, it is difficult

to alleviate all of these barriers for the variety of marginalized identities with a singular initiative. One of the most impactful implemented programs has focused on navigation (Dohan & Schrag, 2005). Although many cancer centers have navigators to assist patients in their battle, having specialized navigation programs that are oriented towards providing equitable care to marginalized groups could provide a more focused and effective approach. At Wake Forest Baptist Comprehensive Cancer Center there are nurse navigators that specialize in assisting various populations, rather than nurse navigators assigned to particular diseases (Strom, 2023). The populations include individuals that identify as immigrants, disabled, Black, Hispanic, and many other underserved populations. Implementing these programs has increased patient compliance and led to higher rates of patients from marginalized groups participating in clinical trials with around a third of rural, Black, and Hispanic patients contributing to research that they are typically underrepresented within (Strom, 2023).

Gaps in Renal Disease Care in Delaware

While kidney disease does not impact as large of a percentage of Delawareans as cancer or other chronic diseases, the consequences can be just as drastic when there are not appropriate public health initiatives in place for these individuals. A large percentage of the population is at risk for developing kidney disease due to having a high blood pressure, being classified as obese, or having a diabetic diagnosis (U.S. Department of Health and Human Services, 2024). Thus, it is important to investigate the holes in the systems in place for both individuals that have kidney disease and those at risk of developing it. An analysis of available resources produced results that demonstrated a few gaps in care that are unique to kidney care, however it moreover provided evidence for similar needs to that of the cancer care programs. Therefore, it is possible that the gaps in care for chronic diseases extends beyond cancer and kidney disease and is a systemic issue in Delaware healthcare.

Access to Transplants and Treatment

One of the largest gaps in renal care in Delaware is access to the most appropriate treatment. ChristianaCare is the only approved location for adult kidney transplant, and with a 30% increase in Delawareans living with kidney failure in the last decade, a singular location is

not sufficient (U.S. Department of Health and Human Services, 2024). Having one option for kidney transplants impacts all individuals that are on the waiting list, and it disproportionately impacts Delawareans with insurance plans that do not cover out of state operations. The location in the northern portion of the state further harms patients from Kent and Sussex county. Continually, the institute has performed around 400 kidney transplants since it began in 2006; 23 were carried out in 2020, while an additional 180 individuals remained on the waiting list (U.S. Department of Health and Human Services, 2024). The easy solution would be to implement additional locations in Kent and Sussex county to increase access to care and the number of transplants completed, however the process to becoming an approved organ donation center is extremely difficult and would require additional surgeons, however it would be beneficial to southern Delaware communities in a longitudinal sense. Despite the fact that there may be fewer individuals visiting the clinic to receive a transplant as compared to the ChristianaCare site, it has been shown that high volume centers are not associated with better outcomes for transplant recipients (Sonnenberg et al., 2019).

Considering the quickly interconnected nature of Delaware through the three major highways, it would be possible to utilize state and/or hospital funded transportation services for individuals in Kent and Sussex county that have difficulties in transportation to the Northern part of the state where the transplant site is located. A second approach to the gap in care would be to take preventative measures to encourage at-risk individuals and individuals currently battling kidney disease to strictly adhere to their treatment plans in order to reduce the number of patients with kidney failure that require kidney transplants. It is common for chronic kidney disease patients to not understand the information about renal disease that is given to them; in a study analyzing the knowledge these patients have of their diagnosis, only 44% of patients knew the cause. Most individuals received their information from family, friends, and television (Danguilan et al., 2013). Patients that were engaged in a community-based kidney disease screening and education program were observed to be more prepared to battle kidney disease and had longer survival after beginning dialysis (Kurella Tamura et al., 2014). However, these two proposals are temporary solutions to the systemic problem of equitable access to renal care facilities across the state.

Financial Resources

Similarly to cancer care, there are not many financial resources across the state of Delaware for individuals battling chronic kidney disease. While the Chronic Renal Disease Program is in place which assists patients with End Stage Renal Disease or who are on dialysis, there are limitations that prevent other patients from obtaining help (*Chronic renal disease program*). Further, there are limited resources to help individuals overcome obstacles that are caused by their disease, but not directly a cost to be covered by insurance. For example, many individuals with chronic kidney disease may not be financially capable of employment due to the demanding schedule that dialysis requires; this may lead to financial distress and food insecurity. Across the United States, approximately half of the nonelderly population battling chronic kidney disease admitted to financial hardships after their diagnosis (Acquah et al., 2021). While patients in Delaware may qualify for the Disability Insurance Program (DIP), the program will not be able to maintain the patient's pay prior to diagnosis. Additionally, family members may be required to sacrifice their employment in order to transport the patient to the dialysis center, compounding the financial burden. The gap in resources provided by both the state and nonprofit organizations impacts individuals of all ages with renal diseases, individuals at risk of developing renal diseases, and their respective family and friends. Financial burdens are not easy to overcome, especially at the population level of all individuals with renal disease. While costs depend directly upon how much the disease has progressed, dialysis treatment costs around \$57,334 per year, and a kidney transplant around \$75,326 per year (Jha et al., 2023). One approach would be to implement patient navigators at facilities that treat Chronic Kidney Disease and End Stage Renal Disease. Patient navigators have been demonstrated to reduce disparities and improve overall outcomes in oncology, and there is currently research in health systems being conducted about the role these individuals could play in other chronic diseases, such as renal disease (Jolly et al., 2015).

Accessible and Reliable Information

A rather imprecise gap in renal care discussion in Delaware relates to the accessibility of information. While there is limited information available about Chronic Kidney Disease, there is no information about End Stage Renal Disease provided online by Delaware-associated web

pages beyond numerical representations of individuals diagnosed. While it is assumed that patients diagnosed with End Stage Renal Disease are provided information by their physicians, this is not accessible to all residents of Delaware. The gap in knowledge provided to residents of Delaware impacts individuals with End Stage Renal Disease, but also those who are at risk of developing it. Simply providing generic information about the disease, as is done with Chronic Kidney Disease in Delaware, would provide sufficient information for individuals in order to guide their lifestyle habits and encourage conversations with their primary care physician. This information could be elaborated upon by including updated information about the functions of healthy kidneys, prevention, appropriate vaccines, etc.

There are few educational programs oriented towards at-risk populations about the severity of kidney disease, and it is not thoroughly covered as much as other chronic diseases such as cardiovascular illnesses. Not all forms of kidney disease are preventable, however there are cases where preemptive measures can be taken to lessen the severity of the disease. The gap in care impacts all Delawareans, but more so individuals that are classified to be at higher risk of developing Chronic Kidney Disease due to ethnicity, blood pressure, weight, and underlying health conditions. The comorbidity associated with cardiovascular disease and Chronic Kidney Disease is undeniable, and controlling the former leads to a more maintainable treatment for the latter (Collins et al., 2010). It has been shown that educational programs and screening initiatives can be effective at determining at-risk individuals that are demonstrating early evidence of CKD and providing the appropriate plan forward (Collins et al., 2010). The National Kidney Foundation developed a screening program that found that 28% of participants had early signs of Chronic Kidney Disease, and a further evaluation of the program demonstrated that the population-level-risk factors can be used to develop educational programs specific to each state's needs (Collins et al., 2010). Therefore, implementing a similar procedure in Delaware may assist in the earlier diagnosis of renal dysfunction and provide individuals with the resources needed to prevent them from developing chronic kidney diseases.

Systemic Issues in Chronic Disease Care in Delaware

While there are many gaps to discuss in relation to each chronic disease individually, it is important to acknowledge the overarching gaps that are common amongst both that point towards a larger issue in Delaware. As the scope of public health continues to broaden and

societal expectations expand, it is imperative that innovative approaches are taken to bridge the gaps in equitable healthcare that are exposed through the medical advancements made in treatment.

Patient Comprehension and Medical Literacy

After reviewing the variety of information and resources provided for both cancer and renal diseases, a consensus can be reached that the information is not oriented towards patient comprehension. Large words that require medical literacy, brief bullet points, and a lack of media make the websites present difficult to navigate and understand. The issue impacts all individuals with chronic disease, but it disproportionately affects individuals with less education. While public schools have been long implemented in order to reduce gaps in literacy rates, 20% of adults in Delaware have literacy levels that puts them at risk of not understanding printed material (University of Delaware Biden School of Public Policy, 2022). Therefore, the complexity of medical terminology only compounds the literacy issue and can lead to the improper transfer of information from physician/government to patient. Innovations have recently been implemented to increase medical literacy and promote advocacy amongst patients. In 2023, Literacy Delaware, a nonprofit that helps adults improve their literacy skills, was granted \$100,000 to support the health literacy program. The funds are allocated for dialysis patients and their families to bridge the health equity gap. However, it is also important to make information available online accessible and comprehensible for all chronic diseases.

Inclusive and Informative Media Forms

While the information is verbose, it is also not accommodating for individuals with varying disabilities and learning styles. For example, visually impaired individuals may find it difficult to access information in a media form that is appropriate, such as audio. Continually, Delaware residents lacking the medical literacy required do not have alternative forms, such as videos, to learn from. While the lack of multimedia platforms for medical information impacts all patients, it unfairly impacts those that rely solely on those forms for comprehension such as the visually impaired illiterate. However, implementing various forms of communication on Delaware's medical web pages could assist in improving patient comprehension, awareness, and action. It was found that two thirds of interventions, including audiovisual, interactive digital, and verbal,

improved all patient outcomes for medical procedures (Glaser et al., 2020). Therefore, it is a possible addition that can be made to increase the accessibility of knowledge and improve adherence to treatment while improving patient outcomes.

Functioning and Reliable Web Pages

A third gap in chronic disease information across the state is the lack of working links and updated information. While online information may not be the primary space for individuals battling chronic disease to gather their information, it is critical that the most updated information is available and that the information presented is comprehensive. A national study done in the early ages of accessible technology found that 47% of individuals seeking out health information through web pages and online resources reported that the information influenced their decisions regarding treatment. The most common topics researched upon included chronic diseases such as cancer and heart disease (Cline, 2001). It can be hypothesized that these percentages have only increased as the internet has become more accessible. Continually, if the websites are equipped with functioning links and attachments to correct information it could prevent the spread of inaccurate knowledge regarding chronic diseases. The gap in care impacts all individuals with chronic diseases, their support systems, individuals that may believe they have a chronic disease, and individuals in Delaware that are researching chronic diseases. While it may be tedious, the most probable solution is to update the various websites across the state that provide information. If all of the relevant information were to be updated onto a singular web page, it would provide patients with an all-inclusive location and prevent the patient from exploring unreliable sites and utilizing false advice.

Chronic illnesses, such as cancer and kidney disease, continue to carry a growing burden for health care institutes in Delaware. Despite the many interventions and programs initiated by the state to alleviate these burdens, there are disparities that still exist across the state. While not designed to be inequitable, there are significantly fewer opportunities for individuals with cancer in Kent and Sussex county to reap the benefits of the innovations in place due to geographical barriers. A similar barrier exists for patients in need of a kidney transplant. Each chronic disease has its own distinct gaps in care, however the state needs to take initiative to overcome the overlapping gaps in care that are experienced by all chronic disease patients. Many of the obstacles experienced for chronic disease patients stem from systemic issues and a lack of

foundational support. The issue is multifaceted and not a singular solution can be implemented. Rather, the gaps in care in Delaware will need to be addressed through multiple initiatives that can be adapted over time to suit the needs of the state.

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